

# Code of Ethical Principles for Genetics Professionals

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*Council of Regional Networks Committee on Ethics*

## INTRODUCTION

The two documents that follow are the fruits of work undertaken by the Council of Regional Networks (CORN) Ethics Committee. The first document, "Code of Ethical Principles for Genetics Professionals," was submitted to the CORN Steering Committee on April 15, 1994 and was accepted by unanimous vote. (Abstentions were by those who had not received the text before the meeting and thus felt that they had not had proper time to study the contents.) This is not a Code of Ethics in the proper sense, but a collection of statements on which consensus could be reached.

The Ethics Committee decided to write an explication of the rather terse statements which make up the accepted document. Thus, the second document contains the text of the first with an interdigitated explication of each of the original statements. These are merely explanations of why the Committee fashioned the accepted statement. The explication has been submitted to the CORN Executive Committee for review. Approval of the explication by the Executive Committee was received October 9, 1995.

The membership of the Committee which produced the two documents remained constant, with the exception of Sarah Comley. The representative from the Mid Atlantic Region Human Genetics Network (MARHGN) was replaced by Frank Seydel as a contributor to the second document. The comments of Dorothy Wertz were of great value in the preparation of this manuscript.

## PREAMBLE

Genetics impacts the health of all individuals, their offspring and future generations. The practice of medical genetics has generated principles of ethics to guide those who strive to serve humanity within this profession. The principal tenets are presented here for the guidance of each professional and the information of the public. The evolution of these principles should be only in the direction of higher levels of service to both the individual and the community, and enhancement of

the freedom and rights of those who come under the care of anyone belonging to the profession.

## GLOSSARY

"Code of Ethical Principles" is a collection of guidelines around which genetics professionals can orient their behavior toward patients, society, and their colleagues.

"Eugenic program" is a public policy intended to change the genetic makeup of the population (vs. eugenic decisions which are made by individual patients in their reproductive choices).

"Genetics professionals" include all of those involved in patient care, and in the delivery of genetics services.

"Genetics services" include all of the medical, laboratory, counseling, support, and information-gathering activities that a genetics professional may carry out in order to serve patient needs.

"Patient" includes anyone receiving genetics services of any kind.

## RESPONSIBILITIES TO PATIENTS AND FAMILIES

The relationships among genetics professionals, patients, and their families are founded on the principles of autonomy and privacy. The genetics professional should:

1. Serve patients and their families with equity and with respect for each person's feelings, beliefs, ethnocultural traditions, and social circumstances;
2. Provide counseling that is nondirective, supportive, and responsive to the individual's requests, and should respect the choices of patients and families;
3. Convey information sensitively to patients, and in language they understand, so that they may make independent decisions and give informed consent;
4. Refer, when indicated or requested, to other experts for specialized services or to confirm diagnosis;
5. Honor the confidentiality of information shared in the relationship with patients and their families;
6. Urge patients and families to share genetic information with relatives at risk, pointing out the possible need for this early in the relationship;
7. Inform persons who participate as subjects of research that they may refuse testing, or refuse to receive information, and that they may withdraw from research programs without change in care;

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8. Inform patients of possible conflicts of interest and of possible commercial and other uses of their biological specimens, of duration of storage, and of confidentiality of personal identifiers.

### RESPONSIBILITIES TO SOCIETY

Individuals within the professional genetics community have a responsibility to provide assistance to society as a whole in the understanding of genetics. Genetics professionals should:

1. Participate actively in the development and support of appropriate regulation of genetics services to ensure that the highest quality is maintained;
2. Achieve appropriate balance between the rights of *individuals* and the needs of public health in the use of genetic information;
3. Promote educational activities designed to inform the community of developments in genetics, and assist the community in formulating reasonable expectations and in understanding implications;
4. Stimulate public discussion of issues arising from advances in genetics, ensure that public debates include objective and well-documented science, and participate in formulation of public policy and attitudes toward genetics to promote socially responsible change;
5. Distinguish, in public statements, that which one perceives as fact, professional consensus, competing schools of thought, or personal opinion;
6. Guard against discrimination on the basis of genetic status, race, gender, sexual orientation, religion, or socioeconomic status in the provision of genetics services;
7. Support equitable access to genetics services as part of any health care system;

8. Support regulation of genetic research that provides ethical standards, including informed consent and confidentiality;

9. Use genetic knowledge and techniques to support and broaden the choice of patients, and not to promote eugenic programs.

### RESPONSIBILITIES TO THE PROFESSION

Genetics encompasses many disciplines in which professionals are trained. Mutual respect and assistance among professionals are essential for proper patient care. Genetics professionals should:

1. Maintain professional competency through continual learning;
2. Share expertise attained through training, experience, and research by teaching, publishing, collegial interchange, and nurturing those who seek competency in the disciplines;
3. Support and encourage one another in ethical conduct, and in resolving professional differences with mutual respect and for the benefit of the patient;
4. Share appropriate information with the referring source, toward the collaborative development of a plan of care for the patient;
5. Guard against the profession's limiting, or cooperating in the limiting, of any individual's or group's human rights on the basis of genetic characteristics.

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